DOCUMENT RESUME

ED 374 635 EC 303 360

AUTHOR Coon, Stephanie M.; Keyes, Denis W.
TITLE Attitudes and Opinions of Preservice Professionals: Withholding Life-Sustaining Treatment from Infants with Severe Disabilities.
PUB DATE 2 Jun 94
NOTE 55p.; Paper presented at the Annual Meeting of the American Association on Mental Retardation (118th, Boston, MA, May 31-June 4, 1994).
PUB TYPE Reports - Research/Technical (143) -- Speeches/Conference Papers (150) -- Tests/Evaluation Instruments (160)

EDRS PRICE MF01/PC03 Plus Postage.
DESCRIPTORS *Attitudes; *Bioethics; College Students; *Education Majors; Elementary Secondary Education; Ethics; *Health Personnel; Higher Education; Infants; *Medical Services; Nurses; Opinions; Premedical Students; *Severe Disabilities; Special Education; Student Attitudes; Undergraduate Study
IDENTIFIERS *Euthanasia

ABSTRACT

This study compares attitudes and opinions of premedical, nursing, regular education, and special education undergraduate students regarding whether life-sustaining treatment should be withheld from newborns with severe disabilities. The paper begins with a review of the literature, which reveals that the amount of experience an individual has with people having disabilities may influence the individual to recommend providing life-sustaining medical treatment, that it may be rare for pediatricians to have any professional experience with individuals having severe disabilities, that special educators were less likely than regular educators to recommend withholding maximum medical treatment, and that the legal decision to administer life-sustaining treatment is left to the individual states. A survey of 131 undergraduate students enrolled at the College of Charleston (South Carolina) or the Medical University of South Carolina is then reported. Results indicate that statistically significant differences among various academic majors occur when comparing views on withholding life-sustaining treatment. Attitudes were affected by choice of major, by experience with individuals having disabilities, and by subject age, but not by gender. Appendices contain a copy of the survey instrument and statistical data. (Contains 22 references.) (JDD)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED 374 635

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
☑ This document has been reproduced as received from the person or organization originating it.
☐ Minor changes have been made to improve reproduction quality.
• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

ATTITUDES AND OPINIONS OF PRESERVICE PROFESSIONALS: WITHHOLDING LIFE-SUSTAINING TREATMENT FROM INFANTS WITH SEVERE DISABILITIES

A Paper Presented at the 118th Annual Meeting of
the American Association on Mental Retardation
June 2, 1994
Boston, Massachusetts

Stephanie M. Coon, M.Ed. Denis W. Keyes, Ph.D.
School of Education, Department of Educational Foundations
University of Charleston, South Carolina
Charleston, SC 29424

BEST COPY AVAILABLE

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY
Denis W. Keyes
TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

EC 303360

TABLE OF CONTENTS

CHAPTER 1 1

Introduction 1

CHAPTER 2 4

Review of the Current Literature 4

Historical Perspectives 4

Legal Challenges 6

Quality of Life Issues 10

Potential Consequences 15

Summary 20

Theoretical Rationale 22

CHAPTER 3 23

Methodology 23

Research Questions 23

Sample 24

Instrumentation 24

Data Collection Procedures 25

Data Analysis Procedures 25

CHAPTER 4 27

Results 27

CHAPTER 5 35

Discussion 35

Summary of Results 35

Limitations 41

Implications for Future Research 42

Conclusions 43

APPENDIX A 44

APPENDIX B 46

REFERENCES 50

LIST OF TABLES

Table 1. Formula for Quality of Life 15
Table 2. Conditions Affecting Decision on Treatment 17
Table 3. Descriptive Statistics for Research Questions 27
Table 4. Oblique Solution Primary Pattern Matrix 28

CHAPTER 1

Introduction

During the past 50 years, medical technology has advanced rapidly. As a result, newborns with severe disabilities, who previously would have perished shortly after birth now have an increased chance for survival. These infants may have severe or profound mental retardation, and often have other serious health impairments. Thus, many of these infants will require extensive personal and medical care throughout their lives by physicians, parents, and educators. They may be unable to function independently in the community as a result of their disabilities, and will likely require a caregiver to help them meet even the most basic needs.

Lay people may question whether life-sustaining treatment should be administered to infants born with such severe disabilities. This ethical dilemma may have occurred because medical technology has advanced faster than legal precedents, particularly in regard to the rights of these infants.

Current law requires physicians to aggressively treat life-threatening medical problems in infants who have severe mental disabilities. As a result, the right to decide what is in the best interests of the child is removed from the parent or other primary caregiver, and the responsibility is placed on the physician.

The concept of the 'sanctity of life' presupposes that every effort must be made to save the life of an infant no matter how medically fragile that infant might be. Furthermore, current legal practice prohibits the discontinuance of life-sustaining treatment of individuals who have severe disabilities (In re: Quinlan, 1976). Still, there are people who believe that the 'quality of life' for newborns who have severe disabilities may be so impaired as to preclude life-sustaining supports (Schalock, 1990). It may be that this belief is held with the

'best interests of the child' at heart. Acceptable 'quality of life' criteria may differ depending on an individual's perception of what is considered 'quality'. Unfortunately, it is unrealistic, and potentially dangerous, to expect one individual to accurately judge the 'quality of life' of another individual. If it is determined that it would be in the best interests of a newborn with severe disabilities to withhold life-sustaining treatment, this may endanger the lives of newborns whose disabilities are not as severe. Society's previous experiments designed to develop a 'super-race', where only the strong are nurtured and allowed to survive, while the disabled are left to die or put to death, should be a warning for the future.

It may be that the fate of newborns who have severe disabilities could be best determined by those who will be actively involved in providing treatment and care to the child throughout his or her life. In reality, however, this does not occur. As previously mentioned, the law requires physicians to provide medical treatment to infants with even the most severe disabilities. Often, the parents of such children may be allowed little or no input as to the fate of their newborn child, even though the parent will likely be that child's primary caregiver (Shelp, 1986). In addition, once life-sustaining treatment has been initiated, it cannot legally be revoked. For example, once an infant has been placed on a ventilator, that child cannot be removed from the ventilator if it means it will result in the infant's death (In re: Quinlan, 1976).

Throughout the life of the infant with severe disabilities, he or she may need to receive extensive or pervasive supportive services. The most important individuals in the infant's life will be his or her parents, the doctor in the delivery room and follow-up care providers, and later, the child's teachers. As the child's primary caregivers, the parents are responsible for meeting the infant's primary needs (e.g., food, water, shelter). The delivery room physician will provide

immediate life-sustaining treatment, and other physicians will continue to provide medical care throughout the individual's life. The teacher's responsibility is to provide the student with an education, opportunities for child success to the greatest extent possible in a normalized setting, and assist the student in becoming a productive citizen.

Physicians treat medical problems that the infant may have but are not responsible for helping that individual establish himself or herself as a functional member of society. Teachers are responsible for educating children, disabilities notwithstanding, and enabling them to succeed in the environment. These professionals will interact with individuals with disabilities in many different aspects of their lives. Medical personnel and educators may have different views on which infants should be given aggressive medical treatment, and which infants will have such a low 'quality of life' that life-sustaining treatment should be withheld.

Since each group of professionals may perceive the newborn with severe disabilities as potentially having different strengths and weaknesses, their different views are important when determining the fate of newborns with severe disabilities. This pilot study compares attitudes and opinions of pre-medical, nursing, regular and special education undergraduate students regarding whether life-sustaining treatment should be withheld from newborns with severe disabilities.

CHAPTER 2

Review of the Current Literature

The dilemma of whether to withhold life-sustaining treatment from infants is not a new one. This debate has existed for thousands of years, though the rapid advance of medical technology in the last 50 years appears to have significantly complicated the issue.

Historical Perspectives

In ancient Greece and Rome, infants who were severely disabled or would be a burden to society were strangled, drowned, buried in dunghills, "potted" in jars to starve to death or exposed to elements . In the *Republic*, Plato encouraged the practice of eugenics. He advocated that the best men and best women, cohabitate "in as many cases as possible and the worst with the worst in the fewest, and that the offspring of one to be reared and that of the other not, if the flock is to be perfect" (Plato, cited in Weir, 1984, p. 8). In *Politics*, Aristotle encouraged the systematic extermination of newborns with disabilities. He states "... let there be a law that no deformed child shall live..." (Aristotle, cited in Weir, 1984, p. 3).

During the middle ages, infants were either abandoned and left to die, or given to a wet nurse with the idea that she would "care" for the infant, when in actuality, she would kill the child. In fifteenth century Italy, many infants with severe disabilities were abandoned in foundling hospitals. Here, infants who otherwise might have been abandoned and left to die by their parents, received some measure of care. (Weir, 1984).

Prior to the nineteenth century, defective children were thought by many to be "demon-children" who had been substituted for the parent's real child. As a result, parents were allowed to "beat the devil" out of the child, usually until the child was dead. Still others regarded the infant with severe disabilities as a

subhuman parasites who sucked "whitened blood" (milk) from the mother's breasts (Weir, 1984). In one instance, when a parent asked for advice on dealing with a 12 year-old child with mental retardation, sixteenth century German Theologian Martin Luther encouraged the parent to throw the "child off a bridge into the water because the child was merely a lump of flesh without a soul (Shelp, 1986, p. 33).

Such practices have existed for thousands of years. The decision to allow an infant with severe disabilities to live or die was usually made by the parents, and later upon the recommendation of the physician or midwife. Even today, many cultures such as the !Kung bushmen in Africa, will destroy an infant that is thought to be a burden to the family or the tribe as a whole. As a whole, western society frowns on the practice of killing infants with severe disabilities, considering extermination of such children to be barbaric (Weir, 1984).

However, Duff and Campbell (1973) stated that between January 1, 1970 and June 30, 1972, forty-three infants in the Yale-New Haven Hospital with various handicapping conditions were left to die "... rather than face a life devoid of meaningful humanhood" (p. 892). This study was one of the earliest to expose the practice of withholding life-sustaining treatment from newborns with severe disabilities. It was suggested that newborns with severe disabilities had a right to die in order to escape what the physicians considered "... a wrongful life" (p. 892). Also, families need to be spared from caring for infants who had no possibility to live a meaningful life (Coulter, 1988; Powell, Aiken & Smylie, 1982; Weir, 1984).

In further studies, Dr. Raymond Duff continues to support the selective nontreatment of newborns with severe disabilities. He believes that many other pediatricians would agree that there are some occasions when death may be a prudent choice, and that choosing death (for a newborn with severe

disabilities) is "... a sorrowful and painful obligation" (p. 62). Hydrocephalus, trisomy 13, trisomy 18, Down Syndrome with complications, and severe forms of spina bifida as conditions that warrant selective non-treatment (Duff, 1976, cited in Weir, 1984).

Legal Challenges

As a result of the study performed by Drs. Duff and Campbell, legal implications of withholding life-sustaining treatment from infants with disabilities was questioned. A case that initially drew the public's attention and first considered the legal ramifications of actions condoned by Drs. Duff and Campbell was that of an infant in the John's Hopkins Medical Center. This infant was initially diagnosed with Down Syndrome and if not treated for a secondary intestinal blockage, would die without corrective surgery. The intestinal defect was correctable, and the surgery virtually risk-free. However, the parents did not authorize the necessary surgery because the infant had additionally been diagnosed with Down Syndrome and treatment was withheld (Hardman & Drew, 1978). This operation would be required for an infant without disabilities, but here the parents were given a treatment option because their child was afflicted with Down Syndrome.

Undoubtedly, the most influential case involving newborns with severe disabilities and life-sustaining treatment was the so-called Baby Doe Case. Baby Doe, a male, was born on April 9, 1982 in Bloomington, Indiana. After birth, it was determined that the baby's esophagus was significantly malformed. This condition is known as esophageal atresia and, as a result, no food would reach the infant's stomach. The esophageal atresia was a secondary to the doctors' diagnosis of Down Syndrome, and the baby would likely be moderately mentally retarded. The physicians informed the parents that the prospects for treating the physical defect were good, but that his mental disability would be

unaffected by this operation (Kuhse & Singer, 1985).

The child's father was a school teacher who had experience with individuals with Down Syndrome. He believed these children never have a minimally acceptable 'quality of life'. After consultation, he and his wife refused to grant permission for the life-sustaining surgery to be performed. As a result, the infant would starve to death in a matter of days (Kuhse & Singer, 1985).

By this time, the administration at Bloomington Hospital had intervened, and petitioned the court for an emergency hearing. At this hearing, the judge determined that , since the parents had been informed regarding treatment options and the potential 'quality of life' their child would have, they had a right to determine the course of treatment. Various 'right to life' groups were enraged, and several individuals offered to adopt the infant. After going through proper channels, a Writ of Certiorari was submitted to the United States Supreme Court, but Baby Doe died prior to the Court's eventual denial of the Writ (Coulter, 1982; Kuhse & Singer, 1985; Lyons, 1985; Powell, Aiken & Smylie, 1982; Weir, 1984).

As a direct result of this case, then President, Ronald Reagan directed Richard Schweiker, Secretary for Health and Human Services, to ensure that the federal laws protecting the rights of infants with disabilities were being adequately enforced (Kuhse & Singer, 1985). A Presidential Memo written at this time stated:

> Our nation's commitment to equal protection of the law will have little meaning if we deny such protection to those who have not been blessed with the same physical or mental gifts we too often take for granted. I support Federal laws prohibiting discrimination against the handicapped, and remain determined that such laws will be vigorously enforced. (Kuhse & Singer, 1985, p. 14)

Section 504 of the Vocational Rehabilitation Act (1973) established that all individuals are endowed with basic rights. These rights are not subject to variable differences, such as age (i.e., infant) or infirmity (i.e., severe mental disability) . Basically, the criteria for providing life-sustaining treatment to individuals with and without disabilities should be the same (Reynolds, 1984). As a result, a 'Notice to Health Care Providers' issued to hospitals was to be posted in all maternity, delivery, pediatric wards, and intensive care nurseries (Kuhse & Singer, 1985). This notice stated it is:

> ... unlawful for a recipient of Federal financial assistance to withhold from a handicapped infant nutritional sustenance or medical or surgical treatment required to correct a life-threatening condition if:
> (1) the withholding is based on the fact that the infant is handicapped; and,
> (2) the handicap does not render treatment or nutritional sustenance contra-indicated. (p. 21)

According to the American Academy of Pediatrics there are certain instances when non-treatment may be feasible. This occurs when the infant (1) has anencephaly; (2) has an intra-cranial hemorrhage; or (3) the infant lacks a substantial part of its digestive tract (Kuhse & Singer, 1985). Any physician who does not follow these guideline is technically guilty of medical neglect and may be held accountable.

In the October Term, 1985, the justices of the United States Supreme Court rejected the argument put forth by the Reagan Administration that Section 504 of the Vocational Rehabilitation Act should allow for federal investigations into decisions regarding the selective treatment of newborns with severe disabilities. The court found no reason to approve federal intervention in these matters which had traditionally been regulated by the individual states. The Supreme Court based their decision on a earlier case, Bowen v. American

Hospital Association, in which no evidence of discrimination was found against infants with disabilities (U.S. Govt. Printing Office, 1986).

Another case that drew the nation's attention regarding the treatment of newborns with disabilities was the case of Baby Jane Doe. She was born on October 11, 1983, and was diagnosed with myelomeningocele, a form of spina bifida, hydrocephaly, and microcephaly. The physicians recommended immediate surgery to reduce the pressure of fluid in her skull, due to the hydrocephaly, and additional surgery to correct the myelomeningocele. The physicians informed the parents this would increase her life expectancy to approximately twenty years, but during that time, she would most likely be severely retarded, epileptic, paralyzed, bedridden, and susceptible to a variety of infections. After a discussion with the physicians, the parents chose not to consent to the surgery (Annas, 1984).

The U.S. Department of Health and Human Services (HHS) received an anonymous complaint that Baby Jane Doe was being "discriminatorily denied indicated medical treatment" (p. 727). The government believed that Baby Jane Doe was denied surgery based on the diagnosis of microcephaly. Eventually, the case was heard before the New York State Court of Appeals which concluded that Section 504 of the Vocational Rehabilitation Act of 1973 did not give HHS any authority with treatment decisions involving newborns with disabilities (Annas, 1984).

However, two weeks prior to this Decision the United States House of Representatives voted in favor of HR 1904, The Child Abuse Amendments of 1984. Among other things, this Act provided that all child protective service agencies, health care facilities, and health professionals develop procedures within a year "to insure that nutrition (including fluid maintenance, *medically indicated treatment*, general care, and appropriate social services are provided

to infants at risk with life-threatening congenital impairments" (Annas, 1984, p. 728, italics added).

The decision to withhold life-sustaining treatment is generally left to the discretion of the individual states, unless the infant is suffering from anencephaly, an intra-cranial hemorrhage, or missing a substantial part of its digestive tract. If these conditions are not present, state law specifically mandates that all other infants be saved. However, many medical experts still differ on the feasibility of saving infants with severe disabilities. Issues that need to be explored are 'Humanness' and the 'sanctity' and 'quality' of life.

Quality of Life Issues

The concept of the 'sanctity' of human life is relatively uncomplicated - equal value is given to all human life regardless of present or future qualities or capacities (Shelp, 1986). Sanford Kadish, writing about the equality of all human lives before the law, states

> ...all human lives must be regarded as having an equal claim to preservation simply because life is an irreducible value. Therefore, the value of a particular life, over and above the value of life itself, may not be taken into account. (Kadish, 1977, cited in Kuhse & Singer, 1985, p.18)

Virtually all babies, regardless of their handicapping condition must be kept alive and to withhold treatment from even the most severely disabled child may legally be considered murder (Kuhse & Singer, 1985; Lyons, 1985).

The issue of "humanness" is a bit more complex. Physicians, ethics, religious experts, and other professionals may have different perspectives on when a being is considered "human". Mary Ann Warren suggests five criteria for "personhood". They are (1) consciousness; (2) reasoning ability; (3) self-motivated activity; (4) capacity to communicate; and (5) presence of self-

awareness. Given this list, it is highly unlikely that an individual with severe disabilities would meet all of these criteria. Warren also believes that the newborn has not yet achieved "personhood" . These infants are allowed to live because the parents desire it, or someone else is paying for care. If the infant is unwanted or defective, and society does not want to support this infant, withholding treatment is permissible (Warren, 1973, cited in Weir, 1984).

Peter Singer, a professor of philosophy at Monash University in Australia, also believes newborns with severe disabilities may not have achieved the status of 'personhood'. Defective infants are replaceable and their lives may be terminated and later replaced by an normal infant born of the same parents. He believes "killing a defective infant is not morally equivalent to killing a person." In fact, "very often it is not wrong at all" (Singer, 1979, cited in Weir, 1984, p. 159).

In fact, in 1977, a task force report to the Anglican Church of Canada stated that infants with severe disabilities did not meet their criteria for 'humanhood'. Their definition of 'humanness' was based on an infant's capacity or potential for making meaningful relationships with other individuals. This report was later rejected by the Anglican Church because it conflicted with traditional values established by the church as well as most other major religions. (Powell, Aiken, & Smylie, 1982). If it is determined that an infant, regardless of the presence of disabilities, is not human, that infant will no longer have certain inalienable rights guaranteed by the United States Constitution to all citizens.

According to Michael Tooley, a professor of philosophy at the University of Western Australia, "... newborns are neither persons nor even quasi-persons, and their destruction is in no way intrinsically wrong" (Tooley, 1983, cited in Shelp, 1986, p. 116). An attempt to further clarify the issue of humanness is

made by Joseph Fletcher, a professor of biomedical ethics. "Any individual who falls below the IQ of 40 on a formal test of intelligence is questionably a person. If the IQ is below 20, the individual is definitely not a person (Fletcher, 1973, cited in Weir, 1984, p. 168)."

One potential problem with Fletcher's definition of 'humanness' is the fallibility of IQ tests. Any scores on a formal test of intelligence below 40 have been statistically extrapolated. Therefore, this may not be considered a 'true' IQ score for the individual. There does not currently exist a formalized intelligence test that has been sufficiently normed on a population including those individuals with severe disabilities. In addition, a developmental scale, such as the Bayley Scales of Infant Development (Bayley, 1969), may give the examiner a more accurate representation of an individual's abilities, but may not be age appropriate. An 'IQ' score is only a global score, and does not provide the examiner with information regarding an individual's specific strengths, or how to best meet the needs of this individual. A low IQ combined with disabilities does not necessarily result in a 'low quality of life', it may only limit opportunities. (Brandt, 1987).

Views on 'humanness' can best be summarized in the following application of the 'humanness' criteria given Fletcher. The father of an infant with Down Syndrome decided to institutionalize his son with the instructions that medical treatment was to be withheld. Fletcher stated that the father should not feel guilt regarding this decision, because guilt is only relevant when wrong is done to a *person*, and in Fletcher's actual words "*... a Down's is not a person* " (Fletcher, 1972, cited in Lusthaus, 1986, p. 149, italics added).

However, former Surgeon General C. Everett Koop, believes that each newborn infant, with and without disabilities <u>is</u> a human being. Following this line of thought, if each living individual is a human being, regardless of

disabilities, then those individuals, born in the United States are guaranteed certain rights under the Declaration of Independence. The first among these being the right to life, liberty and the pursuit of happiness. Koop believes in the sanctity of all life, born or unborn. Accordingly, if an infant is allowed to die as a result of their disability, that infant is being discriminated against (Weir, 1984).

Other physicians, ethicists, and religious experts argue that the 'quality of life' for a newborn with disabilities should be taken into consideration when determining whether to provide life-sustaining treatment (Shelp, 1986; Kuhse & Singer, 1984; Lyons, 1985; Weir, 1984; Powell, Aiken & Smylie, 1982). The term, 'quality of life' presupposes and subsequently judges the value of human life based on certain present or future qualities or capacities (Shelp, 1986). When determining the 'quality of life' of infants with severe disabilities, the cost of pain and suffering must be judged against any potential rewards. Emotional and/or physical pain, must be justifiable in terms that would suggest a reasonable expectation for a happy future. Lyon believes "... there is no hope of producing anything remotely resembling a normal life..." for children with severe disabilities. These children will "... lack mobility, relate to the environment in only rudimentary ways, and may even be in pain" (Lyons, 1985, p. 199). There is no reason to sustain the life of an infant with severe disabilities by using machines just for the sake of keeping them alive. Efforts to keep infants alive in such a hopeless condition is cruel. Many handicapping conditions have the potential to so incapacitate or humiliate the individual as to make their existence more of a burden than a joy for everyone involved (Lyons, 1985).

Reverend James Bresnahan, a medical ethicist, believes that suffering and pain are different concepts: suffering isn't only pain; it is the loss of the ability to do certain things. He believes parental suffering should also be

considered when making the decision to treat a newborn with severe disabilities. The parents suffer out of empathy for the child (Bresnahan, 1985, in Lyons, 1985). Some degree of suffering will most likely accompany any life-sustaining or prolonged medical treatment, and this must be taken into consideration when the treatment decision is made (Weir, 1984).

Regarding the child's best interests, it is important to consider whether death is a better option than remaining alive. The issue is not whether life with certain handicaps is meaningful, but whether to keep the infant alive by extraordinary means is a fate worse than death (Weir, 1984). However, Norman Fost, a pediatrician does not understand what is hopeless about intestinal atresia or Down Syndrome. Infants with severe disabilities are limited only by the restrictions society places upon them (Fost, cited in Weir, 1984).

The perceived level of pain and suffering influences the value placed on human life. When making the decision to treat newborns with severe disabilities, diagnostic information regarding the infant's current condition and valid, existing predictive information, concerning the infant's future abilities, must be considered (Shelp, 1986). By imagining one's self in the place of the infant with severe disabilities, the realization may be reached that it would be kinder to let the child die. By using this technique, it may easier to determine if a life with severe disabilities would be of negative value to the child (Lyons, 1985).

Anthony Shaw, MD., proposes the following formula for determining quality of life (see Table 1). Using this formula, individuals with severe mental disabilities would be viewed as having a low "NE", therefore a less acceptable 'quality of life'.

The term 'quality of life' has become a 'catch-all' phrase and Attorney Lee Dunn, a specialist in health law, offers a caution. In using the term 'quality

of life', people are able to say "We'll withhold care, it's better for the baby." In reality, it may be better for parents. Dunn feels that when parents conceive a child, they have a responsibility for them. Parents have an obligation to provide care and sustenance to that child (Dunn, 1982, cited in Lyons, 1985). In addition, Ruth Luckasson, Regent Professor at the University of New Mexico, fears that continued use of the term 'quality of life' may result in a false justification for the denial of rights for individuals with disabilities. The phrase 'quality of life' may be used to disguise a prejudice against individuals with mental retardation. Finally, Luckasson believes 'quality of life' should not be the basis for any health care decision (Luckasson, 1990).

Table 1. Formula for Quality of Life (Shaw, 1977, cited in Weir, 1984, p. 66).

QL = NE x (H + S)

QL = 'quality of life'
NE = natural physical or intellectual endowment of the child
(H + S) = contributions made to the individual by family, home & society

Potential Consequences

Caution must be used in making the decision to withhold any type of life-sustaining treatment. Initially, infants from which treatment will most likely be withheld are those with clearly recognizable physical defects. This group would include infants with hydrocephaly, spinal myelogysplasia, or anencephaly. However, infants with more readily correctable defects (i.e., duodenal atresia, a condition where the first part of the small intestine ends in a blind pouch) may be allowed to die because of other non-life threatening mental disabilities (Powell, Aiken & Smylie, 1982).

This may be somewhat similar to the "medicalized killing program," a

radical eugenics movement, utilized in World War II Germany. The concept of eugenics follows the belief that killing 'defective' individuals would in some way benefit society. Initially, only newborns with severe disabilities were allowed to die. This concept was later expanded to include individuals with severe mental retardation, cerebral palsy, and eventually Down Syndrome. The decision to withhold treatment from an individual was based on that individual's perceived potential contributions to society (Coulter, 1988; Powell, Aiken and Smylie, 1982). When individuals are denied something based on their inherent qualities, the "slippery slope" scenario may result. This refers to the concept in which, once a process has begun (i.e., withholding life-sustaining treatment from newborns with disabilities), a chain of events is set into motion which cannot be reversed. As a result, infants with less severe disabilities could eventually be denied treatment. Coulter feels the premise of the "medicalized killing" was a concept of "life unworthy of life" (p. 74). Modern society must reject this concept, and acknowledge that all life, no matter how disabled the individual may be, has value (Coulter, 1988).

Today, since more infants with severe disabilities are surviving, parents and physicians are becoming more accountable for the lives and deaths of infants. Since modern medicine now provides physicians with the ability to intervene in life-threatening situations, they must decide when it is appropriate to intervene, and when infants with severe disabilities should be permitted to die. This decision may be accompanied by anxiety because the government or another third party may object to the initial decision and bring criminal charges against parents or physicians who withheld treatment. Because infants cannot express their wishes, others must be trusted to act on their behalf. Logically, one would expect this decision-making process to fall to the parents, since parents will usually look out for the "best interests" of their child (Shelp, 1986).

However, others argue that when parents are confronted with a child with severe disabilities, they must first grieve the loss of the perfect baby they had expected. Parents must then cope with the birth of the feared, threatening, anger-provoking, defective infant born instead (Shelp, 1986). Unfortunately, parents of newborns with severe disabilities may not be as concerned with the best interests of their infant, as with their own perceived best interests. In some cases, the continued existence of a newborn with severe disabilities may be so great a burden to others (i.e., parents) as to render life-sustaining treatment morally optional (Shelp, 1986). As a result, parents have the right to be free from the burden of rearing a defective child (Stevens & Conn, 1976).

In certain situations, the decision not to treat an infant with severe disabilities could be considered justifiable (see Table 2).

Table 2. Conditions Affecting Decision on Treatment. (adapted from Shelp, 1986)

Parents may make a justifiable decision to withhold treatment if:

(1) there is no proven procedure or conflicting medical advice is given;
(2) there is less than a high probability that the result of the treatment will be a normal or near normal life;
(3) the intervention will be futile; or,
(4) the treatment would impose a burden on the infant or others.

Parents may make a reasonable decision to withhold treatment if:

(1) the parents have been provided with and understand accurate information;
(2) there is a brief period of delay after the initial decision is made;
(3) consultants are provided if requested by parents; and,
(4) the infant was made available for adoption.

Other professionals and lay people argue that physicians may be better able than parents to make a rational treatment decision. Physicians may be more capable of distancing themselves or be less affected by stress. In

addition, physicians are presumed to have greater knowledge and, since they have been exposed to many cases, their decisions should be more consistent (Shelp, 1986).

However, physicians may be torn between two conflicting roles. According to the Hippocratic oath, the physician must "... first, do no harm ...", but in the process of saving these infants' lives, physicians may inflict pain and suffering. Shaw (1987) clarifies this issue by stating that treatment is only harmful if a child is allowed to live who otherwise would have died, or if the child is handicapped to such an extent that they "... have little or no opportunity to enjoy life" (p.120). Medical intervention becomes harmful if it prolongs the process of dying.

A potential problem with allowing physicians to make such decisions is that they may be preoccupied, and may have given relatively little thought to the issues involved (Brandt, 1987). In addition, a physician's experiences with individuals with severe disabilities may be quite limited, therefore affecting the ability to form an accurate judgment of the future of an individual with disabilities.

A suggested solution to the problem of which party should make the ultimate treatment decision might be the formation of a hospital ethics committee. Members of this committee would include a physician, a neonatologist, the infant's parents and/or other advocate, an attorney, a nurse, and an individual from a professional organization dealing with individuals with disabilities. Relevant facts would be reviewed, and the final decision should be less biased than one made only by the primary physician and parents (Stevens & Conn, 1976). In addition, a committee would provide some measure of due process for the infant without exposing the family to a formal hearing in court. An ethics committee would bring together a number of professionals with

diverse points of view. Each member's consideration of the situation's positive and negative aspects would, in theory, allow the group to reach a consensus where the best interests of all parties were being served (Lyons, 1985).

In outlining the role of the ethics committee, MacMillan (1978) suggests that physicians would have a minor role in determining the administration of life-sustaining treatment, and whether such treatment is feasible. The actual decision to treat the infant is left primarily to the parents. If the parents decide that treatment is to be withheld, the ethics committee would automatically review the infant's case. The parents retain the right to make the decision regarding treatment, but the newborn's rights are safeguarded by the formal review (MacMillan, 1978, cited in Powell, Aiken & Smylie, 1982).

Unfortunately, problems also exist with the concept of a hospital ethics committee. Often, the decision to administer or withhold treatment must be made quickly, and all members may be unavailable for emergency meetings. As a result, committee members with vital and relevant experience may be absent. There may also be internal problems within the committee, preventing it from functioning fairly or efficiently. In addition, an ethics committee reduces parental autonomy and physician discretion. Parents are allowed to make the initial decision, but if the committee disagrees with that decision, parental rights may be foregone (Shelp, 1986).

In reality, committees can mediate a dispute, but only the courts have the authority to rule on individual cases (Shelp, 1986). If the parents, the physician, or the hospital deny life-saving medical treatment, in the court's view, a crime may have been committed. Some believe parents and physicians may be liable for homicide by omission (i.e., withholding something that results in death). Parents are obliged to feed, clothe, and provide medical care for their children. If they do not fulfill these requirements, they may technically be

committing murder (Lyons, 1985).

Although the ultimate decision regarding withholding treatment from newborns with severe disabilities is made by the courts, several studies have been conducted to determine how different professionals might treat a newborn with severe disabilities. One study asked 457 pediatric surgeons and pediatricians, "Do you believe that the life of each and every newborn should be saved if it is in our ability to do so?" Approximately 83% of the pediatric surgeons and 81% of the pediatricians responded 'No' (Kuhse & Singer, 1986, p. 174; Lyons, 1985, pp. 77-78). Also, a 1983 Gallup Poll of 1540 adults showed that 43% surveyed would ask the doctor not to administer life-sustaining treatment to a newborn with severe disabilities (Gallup Poll, 1983 cited in Lyons, 1985, p 78).

Following the Duff and Campbell (1973) treatise, 54% of surveyed physicians in Massachusetts were not inclined to recommend surgery for an infant with Down Syndrome and duodenal atresia; also, 66% would not recommend surgery for an infant with myelomeningocele, a severe form of Spina Bifida (Todres, 1977, cited in Weir, 1984). More alarming yet, in San Francisco, 22% of pediatricians surveyed favored non-treatment for an infant with Down Syndrome without complications (Hastings Center Report, 1976, cited in Weir, 1984).

Summary

The amount of experience an individual has with people having disabilities may influence them to recommend providing life-sustaining medical treatment. Unfortunately, it may be rare for pediatricians, a group whose recommendations are strongly considered when determining life-sustaining measures, to have any professional experience with individuals having severe disabilities. Without such experience, pediatricians may be unable to make an

unbiased decision (McDaniel, Miller, & Rammler, 1989).

A survey of the attitudes and opinions of regular versus special educators regarding infants with severe disabilities and withholding life-sustaining treatment was performed by McDaniel, Miller and Rammler in 1989. In this study, it appeared that special educators were less likely to recommend withholding maximum medical treatment from newborns with severe disabilities. However, both groups felt the recommendations of parents and doctors should be given consideration in the decision-making process. More regular educators than special educators believe that people with severe disabilities had the potential to live productive lives; however, regular educators were more likely to recommend withholding treatment (McDaniel, Miller & Rammler, 1989).

Currently, the legal decision to administer life-sustaining treatment is left to the individual states. Parents and physicians make this decision together, albeit with more caution and reservations than in the past (Shelp, 1986). Unfortunately, parents may not be knowledgeable of certain conditions that affect their newborn, and even if they comprehend the severity of the infant's disabilities, they may not be emotionally stable enough to make a rational decision (Brandt,1987). Often, parents will follow the suggestions of physicians, since they may be perceived to be omniscient. In reality, the physicians may have had very little practical experience with individuals with severe disabilities (Turnbull, 1983).

Obviously, there is no one individual who is best able to make such important treatment decisions. Family members often make the treatment decision, which may result in excluding someone from the family (Turnbull, 1983). Unless parents are willing to take the infant into their family, there is no reason why they should have the right to make such decisions (Brandt, 1987). If physicians make the treatment decision, it may be based on nonmedical

matters (i.e., developmental potential), an area in which the physician may not be familiar or qualified (Brandt, 1987).

Theoretical Rationale

As mentioned previously, one potential solution to this dilemma may be the formation of an ethics committee composed of various professional disciplines. Four individual disciplines that might be included on this committee are physicians, nurses, special educators, and regular educators. Physicians could be include because they are familiar with various medical conditions and treatment options, and have knowledge of the infant's medical condition. Nurses could be included because they are required to follow orders issued by the physician. If the physician and parents opt not to treat the infant, the nurses may have to watch the infant suffer a slow and, quite possibly, painful death. Special educators may be included because they potentially have developmental experience and an understanding of how an individual with such disabilities will be accepted by society. They also have an awareness of what skills the individual with severe disabilities will need to master. Finally, given the current push for full-inclusion, regular educators may be responsible for interacting and educating individuals with disabilities in a mainstreamed educational setting.

Logically, how a professional perceives an individual with severe disabilities will affect their views, their contributions to the committee, and their treatment recommendations. This pilot study attempts to determine the attitudes and opinions of pre-medical, nursing, special education, and regular education undergraduate majors regarding life-sustaining treatment and newborns with severe disabilities.

CHAPTER 3

Methodology

The current research study was developed to investigate the effects of five independent variables on undergraduate students' attitudes and opinions toward the withholding of life-sustaining treatment from newborns with severe disabilities. The variables are academic major, age, gender, level of experience with people having disabilities, and completion of a course in medical ethics. Attitudes and opinions were measured on an eight item survey instrument.

Research Questions

This study was based on group responses to eight research questions. The first research question stated: Should life-sustaining treatment be administered to newborns with severe disabilities unless it would merely prolong dying? The second research question stated: Should life-sustaining treatment be administered to newborns with severe disabilities unless the parents specifically request their newborn not receive these services? The third research question stated: Should the parents' wishes be considered when determining whether to administer life-sustaining treatment to a newborn with severe disabilities? The fourth research question stated: Should infants with severe mental disabilities be given life-sustaining treatment in an effort to correct medical conditions unrelated to the child's mental disability? The fifth research question stated: Should life-sustaining treatment be able to be terminated at any time upon parental request? The sixth research question stated: Are individuals with severe disabilities able to lead happy, productive lives? The seventh research question stated: Should the decision to administer life-sustaining treatment be determined on an individual case basis,

taking into consideration the severity of the newborn's disability? Finally, the eighth research question stated: Should life-sustaining treatment be administered in all newborn cases, regardless of the presence of any severe disabilities?

Sample

The subjects of this study consisted of a group of 131 undergraduate students, who were enrolled at the College of Charleston or the Medical University of South Carolina. The mean age was 22.68 years, and 19 men and 110 women participated in the study. Two subjects did not offer their ages, and one did not offer gender, resulting in their elimination from the analysis of those variables. Each subject had declared a major in either pre-medicine (premed), nursing, special education or regular education. The were 25 premed, 32 regular education, 34 special education, and 40 nursing majors. Each subject was surveyed based on their declaration of major and availability. It should be noted that this sample was not randomized, which may affect the generalizability of the data.

Instrumentation

Subjects were administered an eight question, Likert-style survey regarding personal attitudes and opinions on newborns with severe disabilities and life-sustaining treatment (See Appendix A). Prior to the development of the survey, a review of the literature did not identify a suitable survey instrument. Based on the results of the review, the principal investigator developed an instrument used in this project. Since this is a new instrument, research on its validity and reliability has not been performed. Therefore, validity and reliability may be suspect, particularly when considering that the reliability and validity on self-report scales may be less than optimal (Brody, Stoneman, Millar, Murray, McCoy, & Kelly, 1990).

Data Collection Procedures

Surveys were administered once to each subject, and took approximately ten minutes to be completed. The administrator briefly explained the purpose of the study and the nature of the participants. In addition to the survey, the subjects were provided with the following definition of severe disabilities:

> -Mental Retardation refers to substantial limitations in present functioning. It is characterized by significantly subaverage intellectual functioning, existing concurrently with related limitation in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work. Mental retardation manifests before age 18. (AAMR, 1992, p. 1)
>
> -Individual with severe disabilities may need extensive or pervasive support in most environments. Extensive support is characterized by regular involvement (e.g.) in a least some environments (such as work or home), and is not time-limited. Pervasive support is characterized by its constancy and high intensity. It is provided across environments and can be life-sustaining in nature. (AAMR, 1992, p. 26)

Subjects were given a five-option numerical range of response, from strong disagreement to strong agreement. Strong disagreement with a research question was indicated by a response of one, while strong agreement was indicated by a response of five. A response of three, indicated no opinion.

Data Analysis Procedures

Each of the eight research questions was examined using two separate statistical procedures. First, an Oblique Solution Primary Pattern Matrix - Orthotran/Varimax Factor Analysis was performed to determine if any items correlated highly with each other. Results of this analysis would indicate if independent research factors existed between the research questions. Second, a one-way factorial analysis of variance (ANOVA) was performed on the separate independent variables for each of the eight research questions.

These variables were academic major, gender, age, experience with individual with disabilities, and completion of a course in medical ethics (e.g., Philosophy 170). This was to determine if subjects significantly differed in their views on each question, based upon the independent variables. Statistical significance was set at the standard Alpha level ($p = .05$). Statistical methods used in the ANOVA procedures included the Fisher PLSD, Scheffe' F-test, and Dunnett t. In addition, simple descriptive statistics were used to determine the mean, standard deviation, and standard error of measurement for each item.

It was expected that certain variables (major, experience with individuals with disabilities, and a course in medical ethics) would be more likely to result in statistical significant differences of responses. However, certain variables were not expected to be significant in identifying response tendencies (age and gender).

CHAPTER 4

Results

Each subject was administered an eight item Likert-style survey to determine attitudes and opinions regarding the withholding of life-sustaining treatment from newborns with severe disabilities. Descriptive statistics were determined (see Table 3), and statistical analyses were performed.

Table 3. Descriptive Statistics for Research Questions - Total Sample.

Question	Mean	Standard Deviation	Standard Error
1	4.008	1.063	.093
2	3.511	1.211	.016
3	4.275	0.92	.08
4	3.752	1.097	.097
5	3.191	1.307	.114
6	3.901	1.115	.097
7	4.262	0.855	.078
8	2.779	1.36	.119

To determine possible relationships between separate questions, an Oblique Solution Factor Analysis was performed on the data results. This analysis determined that there were two clear factors involved in this research, involving seven of the eight research questions (see Table 4).

The results of the factor analysis indicate that items two, three, five, and seven correlated highly, and subsequently emerged as a separate factor in this research, hereafter referred to as Factor One. These items appear to relate to specific case considerations and parental involvement in the decision to administer life-sustaining treatment. Factor Two, comprised of items one, four, and six, appears to deal with individual subject's personal beliefs on withholding life-sustaining treatment and projected 'quality of life' for persons

with severe disabilities. Item eight did not correlate significantly with either factor, and is examined as a separate research question. Results of each analysis are reported.

Table 4. Oblique Solution Primary Pattern Matrix - Orthotran/Varimax on Results of Individual Research Questions.

	Factor 1	Factor 2
Question 1	.192	.623*
Question 2	.712*	.276
Question 3	.824*	.046
Question 4	-.095	.839*
Question 5	.574*	-.257
Question 6	-.074	.719*
Question 7	.739*	.008
Question 8	-.529	.460

A factorial analysis of variance (ANOVA) was performed for each independent variable on each of the two identified Factors, as well as on each research question, including item eight. A one-way factorial analysis of variance (ANOVA) comparing academic majors indicated that there was no statistical significance on Factor One, $F(3, 127) = .454$, $p = 0.715$. This suggests that academic major does not significantly affect responses regarding specific case considerations and parental involvement in the decision-making process. In addition, a one-way factorial analysis of variance (ANOVA) comparing academic majors indicated no statistical significance on Factor Two, $F(3, 127) = 1.449$, $p = 0.23$. This suggests that academic major does not significantly affect individual subject's personal beliefs on withholding life-sustaining treatment and projected 'quality of life' for persons with severe disabilities.

However, when a one-way factorial analysis of variance (ANOVA)

comparing academic majors was performed on item four, an element of Factor Two, statistical significance was noted, F (3, 125) = 3.068 , p= 0.03. Premed subjects and special education subjects differed significantly in their responses, suggesting that group differences may exist in this area. Special education students tended to respond more favorably than premed students, suggesting that the former believe more strongly that infants should be given life-sustaining treatment in an effort to correct medical conditions unrelated to the child's mental disability.

In addition, a one-way factorial analysis of variance (ANOVA) comparing academic majors indicated statistical significance on item five, an element of Factor One, F (3, 127) = 3.614 , p= 0.015. In comparing nursing students with students of other majors, nursing students differed significantly in their responses, indicating group differences in perceptions to this question. Nursing students tended to respond less favorably than either premed, special education or regular education students, suggesting that the former may believe parents should not be allowed to request termination of life-sustaining measures.

Likewise, when a one-way factorial analysis of variance (ANOVA) comparing academic majors was performed on item six, an element of Factor Two, there was a statistically significant difference, F (3, 127) = 3.272 , p= 0.023. In comparing special education students with premed and regular education students, special education students differed significantly in their responses, suggesting group differences in perceptions to this question. Special education students tended to respond more favorably than either premed or regular education students, suggesting that the former believe more strongly that individuals with severe disabilities are able to lead happy, productive lives.

Finally, when a one-way factorial analysis of variance (ANOVA) comparing academic majors was performed on item seven, an element of Factor One, a statistically significant difference was noted, F (3, 126) = 2.608 , p= 0.05. In comparing nursing students with premed, special education and regular education students, nursing students differed significantly in their responses, suggesting group differences in the perception of this question. Nursing students tended to respond more favorably than either premed, special education or regular education students, suggesting that the former believe the administration of life-sustaining treatment should be determined on an individual case basis, taking into account the severity of the newborn's disability.

For item eight, a one-way factorial analysis of variance (ANOVA) comparing academic majors indicated a statistically significant difference, F (3, 127) = 3.919 , p= 0.0103. In comparing special education students with nursing students, special education students differed significantly in their responses, indicating group differences in perceptions of this question. Special education students tended to respond more favorably to the idea that life-sustaining treatment should be administered in all newborn cases, regardless of the presence of any disabilities. Nursing students tended to respond less favorably.

On the second independent research variable, subject gender, a one-way factorial analysis of variance (ANOVA) comparing both males and females on responses to all items, there was no statistically significant difference noted on either Factor One or Factor Two, F (1,127) = 0.189, p = .664; F (1,127) = 0.383, p = .537. It is important to note that females may be overrepresented in the sample, as evidenced by a ratio of approximately five to one. On item eight, gender was also determined to be a less than significant factor, F (1,127) =

0.025, p = .874.

Independent research variable three, subject age, was also investigated. For purposes of analysis, ages were collapsed into five different groupings (18-20, 21-23, 24-26, 27-29, 30+). A one-way factorial analysis of variance (ANOVA) comparing each group on Factor One was performed. Results indicated statistically significant differences existed between several groups, F (4,126) = 3.181, p = .016. In comparing group responses based upon age differences on item two, groups one and two (ages 18-20 and 21-23) tended to respond more favorably to the administration of life-sustaining treatment to newborns with severe disabilities, unless parents specifically request discontinuation of treatment. Members of group five (ages 30 and older) tended to respond less favorably.

A one-way factorial analysis of variance (ANOVA) based upon age differences on item five also indicated statistical significance F (4, 126) = 3.751, p= 0.006. In comparing groups one and two (ages 18-20 and 21-23) with groups four and five (ages 27 - 29; 30 and older), groups one and two tended to respond more favorably to the termination of life-sustaining treatment upon parental request than either group four or five.

Finally, in comparing responses based upon age differences to item seven, statistical significance was noted within specific group references F (4, 125) = 2.037, p= 0.093 (Fisher PLSD = 0.533; 0.761). Groups two and three tended to respond more favorably to the concept that life-sustaining treatment should be determined on an individual case basis. Group five tended to respond less favorably.

A comparison of independent variable three (age) on Factor Two, personal beliefs on withholding life-sustaining treatment and projected 'quality of life' for persons with severe disabilities, did not determine a significant

relationship F (4, 126) = .451, p= 0.771. However, a comparison of responses based upon age differences to item six, an element of Factor Two, statistical significance was noted in specific group references F (4, 126) = 1.648, p= 0.166 (Fisher PLSD = 0.675). Here, group two (ages 21 - 23) tended to respond more favorably to the concept that individuals with severe disabilities are able to live happy and productive lives. Group five (ages 30 and older) tended to respond less favorably.

Finally, age comparisons for item eight did not suggest statistical significance F (4, 126) = .341, p= 0.850. This suggests that age was not a significant factor in determining whether life-sustaining treatment should be administered in all newborn cases, regardless of the presence of severe disabilities.

In comparing independent variable four, subject experience with individuals having severe disabilities, on Factor One, a significant relationship was not established F, (1, 128) = .118, p = 0.732. This suggests that specific case considerations and parental involvement in the decision to administer life-sustaining treatment is not affected by the subjects' experience with individuals having severe disabilities. In checking individual items, this was also found to have no significant effect.

Likewise, in comparing experiential elements on Factor Two, personal beliefs on withholding life-sustaining treatment and projected 'quality of life' for persons with severe disabilities, a significant relationship was not established F (1,128) = .975, p= 0.325. However, a one-way factorial analysis of variance (ANOVA) comparing experience with individuals with disabilities on item six, an element of Factor Two, indicated that there was statistical significance F (1, 128) = 4.536 , p= 0.0351. Respondents who had experience with individuals having disabilities tended to respond more favorably to the concept that people with

severe disabilities can lead happy, productive lives than those without experience.

Finally, experience with people having severe disabilities was not determined to be significant on item eight, F (1, 128) = .256 , p= 0.614. This suggests that experience may not be relevant to the belief that life-sustaining treatment should be administered in all newborn cases, regardless of the presence of disabilities.

The final comparison considered independent variable five, the completion of a medical ethics course, on Factor One, specific case considerations and parental involvement in the decision to administer life-sustaining treatment. Here, no statistical significance was noted F, (1, 128) = .475, p = 0.492. This suggests that the completion of a medical ethics course does not significantly affect attitudes towards Factor One. However, a one-way factorial analysis of variance (ANOVA) of independent variable five and item seven, an element of Factor One, indicated that there was statistical significance F (1, 127) = 4.532, p= 0.0352. A comparison of students who had completed an ethics course with students who had not suggests that students who had completed a medical ethics course tended to respond more favorably to the belief that the administration of life-sustaining treatment should be determined on an individual basis, taking into account the severity of the newborn's disability.

On Factor Two, students who had completed a medical ethics course did not differ significantly from those who had not taken the course F, (1, 128) = 2.19, p = 0.141. Thus, personal beliefs on withholding life-sustaining treatment and projected 'quality of life' for persons with severe disabilities do not appear to be affected by the completion of a medical ethics course. Also, no individual items of Factor Two were significant.

Finally, a comparison of independent variable five and item eight did not indicate statistical significance F, (1, 128) = .596, p = 0.441. Individual subjects who completed a medical ethics course did not significantly differ from others in their beliefs that life-sustaining treatment should be administered in all newborn cases, regardless of the presence of disabilities.

CHAPTER 5

Discussion

The current research study compares attitudes and opinions of pre-medical, nursing, regular and special education undergraduate students regarding whether life-sustaining treatment should be withheld from newborns with severe disabilities. These professionals in training may have a unique present or future role in helping individuals with severe disabilities establish themselves as functional members of society. They will likely hold different views on criteria to determine which infants should be given aggressive medical treatment, and/or on perceptions of which infants may have such a reduced 'quality of life' that life-sustaining treatment should be withheld. Since members of each profession may perceive newborns with severe disabilities as potentially having various strengths and weaknesses, the resulting different viewpoints are important when determining the fate of newborns with severe disabilities.

Summary of Results

Results clearly indicate that certain survey items highly correlate to each other, as confirmed in the factor analysis. The two factors deigned from the eight research questions appear to affect responses involving specific case considerations and parental involvement (Factor One) and individual subject's personal beliefs on withholding life-sustaining treatment and projected 'quality of life' for individuals with severe disabilities (Factor Two). Item eight did not significantly correlate to either factor, and was investigated as a separate research question.

The research items of the survey instrument were randomly ordered, with

the exception of item eight. Since item eight implied that life-sustaining treatment should be administered in all newborn cases, regardless of the presence of any disabilities, it was placed last. If this item was placed earlier in the instrument, subject responses to that question might potentially influence responses on the remaining survey items. While this was not necessarily the case, item eight did correlate directionally with each factor, and its importance is unquestionable.

The lack of significance between academic majors and both Factors One and Two seems to suggest that academic major may not play a role in group beliefs and attitudes toward individuals with disabilities. This is significant because one might expect special educators, physicians, and/or nurses to hold stronger, and potentially more favorable opinions regarding beliefs regarding the lives of individuals with severe disabilities. Still, ANOVA results of individual item and academic majors established significance on five separate research items.

For example, nursing students tended to respond less favorably than the premed, special education, and regular education students to the parental requests for the termination of life-sustaining treatment. In hospital settings, the nurses are primarily responsible for following the physicians' orders. If the parents decide to terminate treatment, and the physician agrees, the nursing staff will likely have to view the resulting death. It might be posited that nurses believe that withholding treatment may result in excruciating pain and suffering that no individual, disabled or otherwise, should be forced to endure. Additionally, nurses may feel that the parents are unaware of the specific circumstances of their infant's disability, and therefore are essentially unable to make an 'informed decision' regarding the withholding of life-sustaining treatment.

Nursing students also responded more favorably than other majors to the concept that life-sustaining treatment should be administered on an individual case basis, taking into account the severity of the newborn's disability. Nurses are responsible for the care of infants having various disabilities, and could potentially be familiar with related treatments and prognoses for the possible future life of newborns with severe disabilities. As a result, nurses may have been involved in situations where different recommendations were made for infants having similar disabilities. Therefore, nurses may believe that the prognosis for an infant with severe disabilities should be determined by several factors, including the combination of mental and physical disabilities, the severity of disabilities, as well as the supportive nature of the home environment. As a result, nurses may believe that different treatment recommendations should be made based on a combination of factors.

Special education students tended to respond more favorably than premed students to the belief that infants with severe mental disabilities should be given life-sustaining treatment in effort to correct medical conditions unrelated to the mental disability. This might be due to the fact that special educators will interact with individuals having disabilities in completely different circumstances than physicians. These interactions may allow special educators to form high positive outlooks for the mainstreamed success of individual having disabilities. As a result, special educators may feel that every effort should be made to correct physical defects, thus increasing potential benefits of education. In other words, once the physical defect is corrected, individuals with severe mental disabilities will potentially be better able to function within the specified environments they will inhabit. Since physicians may have little or no experience with individuals having such severe disabilities, they may project a lower expectation for the 'quality of life' of these individuals, and therefore

believe that withholding life-sustaining treatment may be in the infant's best interest.

It was also determined that special education students tended to respond more favorably than nursing students to the belief that life-sustaining treatment should be administered in all newborn cases, regardless of disabilities. As a result of their experiences in working with individuals having disabilities, special educators may have reached the conclusion that there is value to all human life, regardless of disability, and therefore must be sustained. Conversely, nurses must watch the pain and suffering involved in saving the lives of infants with severe disabilities. Nurses may believe that instances occur when it is best to let the infant die, rather than implement extraordinary means to extend the life of an infant with severe disabilities by a few years.

Perhaps most importantly, special education majors tended to respond much more favorably than premed or regular education students to the belief that individuals with disabilities can live happy and productive lives. Again, special educators will likely interact more extensively with individuals having severe disabilities than either physicians or regular educators. As they are responsible for preparing individuals with disabilities to function in society, special educators are more familiar with the potential accomplishments of individuals with disabilities than either physicians or regular educators. It is logical that the special educator would project a higher expectation for these individuals to lead happy, productive lives.

The lack of significance between gender and Factors One, Two, and Item 8, suggests that subject gender does not influence attitudes and opinions regarding individuals with severe disabilities. Gender did not significantly affect responses involving specific case considerations, parental involvement, the subject's personal beliefs on withholding life-sustaining treatment, or projected

'quality of life' for individuals with disabilities. While females may appear to be overrepresented in this sample (ratio - 5:1), if the sample were to be compared to the stratified demographics of the population of these professions, there may be no significant overrepresentation.

The responses of different age groups suggest that younger individuals feel the parents should be allowed greater involvement in the decision to withhold treatment than older subjects. Given the assumption that older subjects may more likely be parents, they could also be more capable of placing themselves in the position of having to make such traumatic decisions. However, it is important to note that group two may be significantly overrepresented (N=84), and results could be skewed. In addition, older subjects were more likely to be nursing students, who, as a group, responded that parents should not be allowed to request the termination of life-sustaining treatment. Older subjects' lower responses may also be because they, as parents, have a clearer idea of how difficult it would be to make this decision, and more aware of how uninformed they might feel about their infant's condition.

One younger group, ages 21 to 23, responded more favorably to the concept that individuals with severe disabilities are able to live happy and productive lives, while older subjects again tended to respond less favorably. Previously, special education students had differed significantly from other groups in the belief that individuals with disabilities were able to enjoy an acceptable 'quality of life'. Since the majority of special education majors were also members of the 21 to 23 age groups, this may have contributed to the significance found regarding this issue.

Each of the five groups disagreed with the administration of life-sustaining treatment in all newborn cases. This suggests that the subjects,

regardless of their academic major, do believe that certain situations exist when it is permissible to withhold life-sustaining treatment.

Subject experience may not be a factor in responses involving specific case considerations, parental involvement, the subject's personal beliefs on withholding life-sustaining treatment, or projected 'quality of life' for individuals with disabilities. However, respondents who had experience tended to respond more favorably to the concept that people with severe disabilities may be capable of living happy, productive lives. Apparently, a subject experienced with individuals having severe disabilities, may project a higher 'quality of life' for these individuals. Given the four academic majors selected for this pilot study, those who would naturally be most likely to have experience with individuals having disabilities are special educators. Therefore, as previously mentioned, special educators may project a higher expectation for these individuals to lead happy, productive lives than either nurses or physicians.

Finally, the lack of significance in the comparison of the completion of a medical ethics (Philosophy 170) to Factors One, Two and item eight seems to suggest that the completion of a medical ethics course does not significantly affect attitudes towards specific case considerations and parental involvement in the decision to administer treatment. However, the majority of individuals who had completed an ethics course were nursing majors. As previously mentioned, this group did not believe parental desires should be considered in the decision to withhold life-sustaining treatment. It is interesting to note that students who had completed an ethics course tended to respond more favorably to the concept that treatment should be determined on an individual cases basis. Once again, the majority of individuals who had completed an ethics course were nursing students. Previously, the nursing students had differed significantly from the other academic majors in the belief that treatment

should be determined on an individual case basis.

Respondents who had completed an ethics course did not differ significantly in their personal beliefs regarding the withholding life-sustaining treatment and projected 'quality of life' for persons with severe disabilities. This is surprising, because the completion of a medical ethics course would be expected to affect beliefs on life-sustaining treatment. One explanation for this lack of significance may be because the majority of subjects had not completed a medical ethics course. In fact, a medical ethics course is not currently required for regular education, special education, or premed majors at this institution.

In addition, subjects who have completed a medical ethics course did not differ significantly in their beliefs that life-sustaining treatment should be administered in all newborn cases, regardless of the presence of disabilities. Both groups appeared to have similar views regarding the belief that some instances may occur when it might be in the best interest of the infant to withhold life-sustaining treatment.

Limitations

The survey instrument developed for this pilot study is new; and, validity and reliability data were not readily available. However, the factors observed suggest that individual research questions could conceivably be used as a measure to predict possible responses to other, correlated questions within Factors One and Two. This suggests at least an adequate level of one form of validity for individual items of the survey, predictive. In addition, research question eight correlates negatively with Factor One and positively with Factor Two. This separates it as a research entity and may potentially positively affect the validity of the instrument.

The size of the sample was adequate; however, two groups, females and

students ages 21 - 23, may be overrepresented. It should be noted that, in three of these professions (nurses, special educators, and regular educators) females may be overrepresented when compared to the general population. The ratio of students between ages 21 - 23 may be overrepresented when compared to the entire population (3:1). However, if the sample was stratified by age of undergraduate students in the population, the appearance of the overrepresentation may not be as significant. The obvious geographic limitation is also a possible threat to the validity and generalization of these data.

Finally, the instrument did not determine if sample subjects were parents. This sixth independent variable would have enabled the attitudes and opinions of subjects having children to be compared with subjects who do not. It would have helped to determine if parenthood affects the views of the subjects toward life-sustaining treatment for infants with severe disabilities.

Implications for Future Research

This study should be replicated at other institutions of higher education using identical or similar academic areas. This would confirm the generalizability of the results of the current study, and possibly the validity and reliability data on the research instrument itself. Different institutions may emphasize different philosophies, resulting in different undergraduate perceptions toward life-sustaining treatment for newborns with severe disabilities.

In addition, a parallel study should be performed using medical students and graduate students in special education, regular education, and nursing. This would enable the determination of attitudes and opinions of subjects who were enrolled in higher level courses regarding the withholding of life-sustaining treatment from newborns with severe disabilities. It may be possible

that significant differences in views on withholding life-sustaining treatment may increase as the subjects progress in their academic study.

Finally, a similar study could be performed with professionals having several years experience in the areas of neonatal and pediatric medicine, special education, regular education and nursing. After years of experience in these professions, personal beliefs regarding parental involvement in the administration of treatment, potential 'quality of life', and the withholding of life-sustaining treatment may change considerably. The subjects' experiences with individuals having disabilities may increase or become even more limited depending on their profession. As a result, the differences between groups may become even more disparate.

Conclusions

Results of the current research study indicate statistically significant differences between various academic majors occur when comparing views on withholding life-sustaining treatment from newborns with severe disabilities. The attitudes of subjects appear to be affected not only by their choice of major, but also by experience with individuals having disabilities and subject age. Subjects having experience tended to view individuals with severe disabilities as having greater potential for leading productive lives. Thus, students in these four academic majors may significantly benefit from some type of study regarding individuals with severe disabilities. In addition, there is little doubt that students majoring in these areas would benefit from increased experience and involvement with individuals having disabilities. The amount of time subjects spend with individuals having disabilities will positively influence the attitudes and opinions they hold regarding the administration of life-sustaining treatment for infants with severe disabilities, and their potential for leading happy, productive lives.

APPENDIX A

INSTRUMENT ADMINISTERED TO PREMED, REGULAR EDUCATION, SPECIAL EDUCATION AND NURSING STUDENTS

Circle only one each, please.

Your major is: premed special ed regular ed nursing

You are a male female.

Your age is: 18-20 21-23 24-26 27-29 30+

You have had experience with individuals with disabilities: yes no

You have completed Philosophy 170 or other medical ethics course: yes no

Please take a few minutes to complete this survey regarding attitudes and opinions of life-sustaining treatment for newborn infants with severe disabilities. Please rate your *personal* opinion. The scale is:

1 = Strongly disagree 2 = Disagree 3 = No opinion 4 = Agree 5 = Strongly agree

1. Life-sustaining treatment should be administered unless it would merely prolong dying.

1 2 3 4 5

2. Life-sustaining treatment should be administered unless the parents specifically request their newborn with severe disabilities not receive life support.

1 2 3 4 5

3. The parents' wishes should be considered when determining whether to administer life-sustaining treatment to a newborn with severe disabilities.

1 2 3 4 5

4. Infants with severe mental disabilities should be given life-sustaining treatment in effort to correct medical conditions unrelated to the child's mental disability.

1 2 3 4 5

5. Life-sustaining treatment should be terminated at any time upon parental request.

1 2 3 4 5

6. People with severe disabilities can lead happy, productive lives.

1 2 3 4 5

7. The decision to administer life-sustaining treatment should be determined on an individual case basis, taking into consideration the severity of the newborn's disability.

1 2 3 4 5

8. Life-sustaining treatment should be administered in all newborn cases, regardless of the presence of severe disabilities.

1 2 3 4 5

APPENDIX B

DESCRIPTIVE STATISTICS FOR INDIVIDUAL GROUPS:

PREMED, NURSING, SPECIAL EDUCATION, AND REGULAR EDUCATION

Question 1: Life-sustaining treatment should be administered unless it would merely prolong dying.

Group	Mean	Standard Deviation	Standard Error
Premed	4.00	1.08	.216
Nursing	4.075	0.797	.126
Special Ed.	3.824	1.336	.229
Regular Ed.	4.125	1.04	.184

Question 2: Life-sustaining treatment should be administered unless the parents specifically request their newborn with severe disabilities not receive life support.

Group	Mean	Standard Deviation	Standard Error
Premed	3.52	1.194	.239
Nursing	3.45	1.154	.182
Special Ed.	3.824	1.336	.229
Regular Ed.	3.75	1.218	.215

Question 3: The parents' wishes should be considered when determining whether to administer life-sustaining treatment to a newborn with severe disabilities.

Group	Mean	Standard Deviation	Standard Error
Premed	4.200	0.764	.153
Nursing	4.35	0.834	.132
Special Ed.	4.118	1.038	.178
Regular Ed.	4.406	1.012	.179

Question 4: Infants with severe mental disabilities should be given life-sustaining treatment in an effort to correct medical condition unrelated to the child's mental disability.

Group	Mean	Standard Deviation	Standard Error
Premed	3.208	1.414	.289
Nursing	3.744	0.993	.159
Special Ed.	4.059	1.099	.189
Regular Ed.	3.844	0.808	.143

Question 5: Life-sustaining treatment should be terminated at any time upon parental request

Group	Mean	Standard Deviation	Standard Error
Premed	3.52	1.295	.259
Nursing	2.65	1.292	.204
Special Ed.	3.324	1.273	.218
Regular Ed.	3.469	1.218	.215

Question 6: People with severe disabilities can lead happy, productive lives.

Group	Mean	Standard Deviation	Standard Error
Premed	3.64	1.114	.223
Nursing	3.85	1.122	.177
Special Ed.	4.382	1.045	.179
Regular Ed.	3.656	1.066	.188

Question 7: The decision to administer life-sustaining treatment should be determined on an individual case basis, taking into consideration the severity of the newborn's disability.

Group	Mean	Standard Deviation	Standard Error
Premed	4.04	0.841	.168
Nursing	4.575	0.636	.101
Special Ed.	4.152	1.064	.185
Regular Ed.	4.156	0.92	.163

Question 8: Life-sustaining treatment should be administered in all newborn cases, regardless of the presence of severe disabilities.

Group	Mean	Standard Deviation	Standard Error
Premed	2.76	1.332	.266
Nursing	2.275	1.176	.186
Special Ed.	3.324	1.471	.252
Regular Ed.	2.844	1.298	.229

REFERENCES

American Association of Mental Retardation (1992). Mental Retardation: Definition, Classification, and Systems of Support. AAMR.

Annas, G.J. (1984). The case of Baby Jane Doe: Child abuse or unlawful intervention? American Journal of Public Health, 74(7), 727-729.

Bayley, N. (1969). Bayley scales of infant development. San Antonio, TX: Psychological Corporation.

Brandt, R. B. (1987) Public Policy and life and death decisions regarding defective newborns. In R. C. McMillan, H. T. Engelhardt, and S. F. Spicker (Eds.), Euthanasia and the Newborn (pp. 191-208). Boston: D. Reidel Publishing Company.

Brody, G.H., Stoneman, Z., Millar, Murray, McCoy, & Kelly, J. (1990). Assessing individual differences. Journal of Personality Assessment, 54(1,2), 401-411.

Coulter, D.L. (1988). Beyond baby doe: Does infant transplantation justify euthanasia? TASH Journal, 13(2), 71-75.

Duff, R.S. & Campbell, A.G.M. (1973). Moral and ethical dilemmas in the special-care nursery. The New England Journal of Medicine, 289, 890-894.

Feldman, D. & Gagnon, J. (1986). StatView 512+ (Version 1.1): The Interactive Statistics and Graphics Program. Calabasas, CA: BrainPower, Inc.

Hardman, M.L. & Drew, C.J. (1978). Life management practices with the profoundly retarded: Issues of euthanasia and withholding treatment. Mental Retardation, 16(12), 390-396.

In re: Quinlan; 70 N.J. 10, 355 A2d 647 (1976).

Kuhse, H. & Singer, P. (1985). Should the Baby Life? The Problem of Handicapped Infants. Oxford: Oxford University Press.

Luckasson, Ruth (1990). A lawyer's perspective on quality of life. In R. L. Schalock (Ed.), Quality of Life: Perspectives and Issues (pp. 177 - 189). American Association on Mental Retardation.

Lusthaus, E.W. (1985). Involuntary euthanasia and current attempts to define persons with mental retardation as less than human. Mental Retardation, 23, 148-154.

Lyon, J. (1985). Playing God in the Nursery. New York: W. W. Norton and Company.

McDaniel, E.A., Miller, R., & Rammler, L.H. (1989). Nontreatement of newborns with severe handicaps: A survey of attitudes of regular and special educators. DPH Journal, 10(2), 78-87.

Powell, T.H., Aiken, J.M., & Smylie, M.A. (1982). Treatment or involuntary euthanasia for severely handicapped newborns: Issues of philosophy and public policy. TASH Journal, 6(4), 3-10.

Shaw, M. W. (1987). When does treatment constitute a harm? In R. C. McMillan, H. T. Engelhardt, Jr., and S. F. Spicker (Eds), Euthanasia and the Newborn (pp. 117-137). Boston: D. Reidel Publishing Company.

Shelp, E.E. (1986). Born to Die? Deciding the Fate of Critically Ill Newborns. New York: The Free Press.

Stevens, H. A. & Conn, R.A. (1976). Right to life/Involuntary pediatric euthanasia. Mental Retardation, 14(6), 3-6.

Turnbull, H.R., (1983). Fundamental rights, Section 504, and Baby Doe. Mental Retardation, 21(5), 218-221.

U.S. Government Publishing Office. (1986). Court rules on abortion, 'Baby Doe' rules. Congressional Quarterly Almanac, pp 263-265.

Weir, R.F. (1984). Selective Nontreatment of Handicapped Newborns: Moral Dilemmas in Neonatal Medicine. New York: Oxford University Press.